

AD_____

AWARD NUMBER: W81XWH-06-1-0463

TITLE: Supporting Connectivity for Biomedical Research

PRINCIPAL INVESTIGATOR: Michael McGill, Ph.D.

CONTRACTING ORGANIZATION: Internet2
Ann Arbor, Michigan 48108

REPORT DATE: May 2006

TYPE OF REPORT: Final Proceedings

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

REPORT DOCUMENTATION PAGE				<i>Form Approved</i> OMB No. 0704-0188	
<small>Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.</small>					
1. REPORT DATE (DD-MM-YYYY) 01-05-2006		2. REPORT TYPE Final Proceedings		3. DATES COVERED (From - To) 24 Apr 2006 – 24 May 2006	
4. TITLE AND SUBTITLE Supporting Connectivity for Biomedical Research				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER W81XWH-06-1-0463	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Michael McGill, Ph.D. E-Mail: mmcgill@internet2.edu				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Internet2 Ann Arbor, Michigan 48108				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT No abstract provided – see Executive Summary.					
15. SUBJECT TERMS No subject terms provided.					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT UU	18. NUMBER OF PAGES 24	19a. NAME OF RESPONSIBLE PERSON USAMRMC
a. REPORT U	b. ABSTRACT U	c. THIS PAGE U			19b. TELEPHONE NUMBER (include area code)

ABBREVIATIONS USED

AHIC	American Health Information Community
AHRQ	Agency for Healthcare Research and Quality
BIRN	Biomedical Informatics Research Network
BISTI	Biomedical Information Science and Technology Initiative
caBIG	Cancer Bioinformatics Grid
CERMUSA	Center of Excellence for Remote and Medically Underserved Areas
CI-TEAM	Cyberinfrastructure Training, Education, Advancement, & Mentoring
EHR	Electronic Health Record
ePCRN	Electronic Primary Care Research Network
HDC	Health Disparities Collaboratives
HRSA	Health Resources and Services Administration
IDeA	Institutional Development Award
IHS	Indian Health Service
INBRE	IDeA Networks of Biomedical Research Excellence
IP	Internet protocol
ISP	Internet service provider
IT	Information technology
LEARN	Lonestar Education and Research Network
MHS	Military Healthcare System
MIDAS	Modeling of Infectious Disease Agent Study
NCBC	National Centers for Biomedical Computing
NCRR	National Center for Research Resources
NECTAR	National Electronic Clinical Trials and Reporting
NEON	National Ecological Observatory Network
NIH	National Institutes of Health
NITRD	Networking and Information Technology Research and Development
NLR	National Lambda Rail
NSF	National Science Foundation
PBRN	Primary Care Practice-Based Research Networks
RCMI	Research Centers in Minority Institutions
REN	Research and education network
RON	Regional optical network
RPMS	Resource and Patient Management System
SURA	Southeastern Universities Research Association
TATRC	Telemedicine and Advanced Technology Research Center
TX	Transit exchange
VHA	Veterans Health Administration

EXECUTIVE SUMMARY

WORKSHOP PURPOSE AND OBJECTIVES

High-speed computer networks are vital to biomedical research, yet the infrastructure supporting network connectivity remains unevenly distributed. This workshop joined together biomedical researchers, networking experts, and computer scientists (Appendices 1 and 2) to identify key challenges to improving network connectivity and utilization across a broad spectrum of users, including those with access to cutting-edge networks and those with little or no connectivity. A draft white paper developed by NCRR, TATRC, and Internet2 staff with help from experts in relevant fields was circulated to participants prior to the workshop to frame discussions at the executive session. The charge to the group at the executive session was to identify key needs and priorities for cyberinfrastructure development during the next 3 to 5 years and to examine best practices for implementing collaborative networks driven by research opportunities across the health research spectrum:

- **Basic Biomedical and Behavioral Research**
- **Clinical and Translational Research**
- **Health Care Quality, Safety and Effectiveness Research**
- **Health Disparities in Underserved Populations**
- **Public Health Monitoring, Biosurveillance, and Situational Awareness**
- **Interdisciplinary Research Training and Education**
- **Health Information Dissemination to Community Providers & Patients**

The workshop encouraged efforts to strengthen partnerships among funding agencies, academic organizations, and the private sector to better coordinate, expand, and optimize investments in network infrastructure. In particular, the workshop highlighted the need to leverage the natural intersections between health research and health care in order to broaden community participation and facilitate development of clinical and translational research networks. The workshop began with presentations from NIH- and TATRC-supported researchers illustrating the range of projects that can be pursued through the formation of appropriately provisioned networks (Appendix 3). The presentations outlined key challenges and lessons learned and focused on best practices:

LESSONS LEARNED

- **Connectivity involves people, projects, and software as well as pipes.**
- **Connectivity serves multiple purposes, so plan accordingly:**
 - **Research (*especially* interdisciplinary research),**
 - **Education and research training, and**
 - **Public service, e.g., improvements in health care delivery.**

Following the presentations, a facilitated discussion session, moderated by Steve

Corbato, Internet2, and co-facilitated by Mark Ellisman, UC-San Diego (representing the research applications perspective), and David Lassner, University of Hawaii (representing the academic IT provisioning perspective), addressed five key questions posed in the white paper and formulated answers reflecting the needs of the health research community:

KEY QUESTIONS AND CHALLENGES

1. Is existing network infrastructure adequate to support interdisciplinary research across the health science spectrum? Will refinement or expansion of current network models suffice to meet anticipated needs, or are new models needed?

- Better connections are needed – both in terms of bandwidth and quality of service – to serve diverse end users who are situated in widely diverse research environments.
- Advanced research applications (e.g., data visualization, real-time event monitoring) are expected to continue to drive increased needs for bandwidth and better quality of service.
- Bandwidth constraints are becoming increasingly critical as the complexity and volume of research data grows, especially for developing institutions.

2. Is existing network infrastructure adequate to bridge academic health centers and community health care providers in order to foster and stimulate community-based clinical and translational research? If not, what are the gaps, what will it take to close them, and how should efforts to close them be funded and prioritized?

- R&D for advanced applications (e.g., medical imaging, remote surgery, emerging point-of-care technologies) requires increased bandwidth and quality of service.
- Low bandwidth and quality of service hinder patient encounters in community research settings, especially in underserved areas
- In some locations, primarily rural locations, commercial “broadband” (cable or DSL) is unavailable at any price due to market constraints.
- Unpredictable latency can be a major impediment for busy physicians wishing to engage in community practice-based research.

3. What are the needs of minority-serving institutions and institutions in rural or remote areas, and how can these needs be addressed to enhance opportunities for broader inclusion in biomedical research?

- Minority-serving institutions (MSIs) and remote/rural institutions often have different issues and needs and should not necessarily be lumped together when considering possible approaches or IT solutions.
-

- Even urban MSIs can lack last-mile connectivity to advanced networks like Internet2 or National Lambda Rail.
- Key common issues for developing institutions are staff and funding constraints for IT infrastructure for research.
- In order for them to be able to effectively participate, developing institutions *must* be included early in the planning process for initiatives designed to promote collaborative research networks.

4. Will the private marketplace and/or state and local governments be willing and able to shoulder the costs of developing and sustaining network infrastructure that meets anticipated research needs and ensures broad access to national and international research assets?

- Emerging regional optical networks (RONs) could help close the gaps between research institutions and high-speed Internet backbones.
- In concert with networking groups such as Internet2 and the National Lambda Rail and aided by a continuously updated inventory of RONs, federal science agencies could serve as matchmakers to help grantees identify appropriate, affordable connections.

5. If further development and expansion of research networks requires federal support, how can funding agencies balance the needs of their own missions against opportunities for collaboration where mutual interests exist? If collaborative approaches are warranted, how will agencies ensure adequate planning, coordination, and evaluation of inter-agency programs?

- Increase communication between federal programs with mutual interests, e.g.,
 - NIH, AHRQ, HRSA, IHS for community-based research,
 - NIH, NSF, DoE for high-performance distributed computing.
- Exploit existing government-wide forums, e.g.,
 - Networking and Information Technology Research and Development (NITRD) Coordinating Groups, and
 - American Health Information Community (AHIC).

PRIORITY RECOMMENDATIONS

- **Strengthen communication and coordination between federal funding agencies, academic groups, and the public and private sectors.**
 - **Exploit existing government-wide forums to promote interagency collaboration.**
 - **Nurture a culture of collaboration in academic health centers to foster**
-

interdisciplinary team science.

- Based on driving research projects
 - Communication across disciplines
 - Data sharing inducements
 - Academic rewards, recognition
 - **Increase support for IT personnel.**
 - Professional project management: bridging the scientific disciplines
 - Operational project management: performance sites and data
 - Ongoing technical support
 - **Increase support for software engineering and maintenance to enable collaborative sharing on a production scale.**
 - **Develop network performance measurement tools and an inventory of network resources and connections.**
 - Common performance standards based on end-user experience
 - First-mile connectivity atlas, state-by-state
 - Decision support tools for getting connected (LAN/WAN cookbook)
 - **Assess bandwidth and quality-of-service needs as a function of application type (e.g., text files vs. streaming audio/video).**
 - **Close wide gaps in connectivity.**
 - Developing academic institutions
 - Rural and remote research sites
 - **Enhance connections to communities and health care providers.**
 - Community-based clinical and translational research
 - Health care quality, safety, & effectiveness research
 - Rapid flow of health information to promote healthy behaviors in communities, to better inform academic research, and to increase situational awareness (e.g., biosurveillance)
 - **Support planning grants to foster the development of collaborative research networks spanning the entire health science spectrum.**
-

SUPPORTING CONNECTIVITY FOR BIOMEDICAL RESEARCH

1. DRIVING RESEARCH OPPORTUNITIES

1.1 *Basic Biomedical and Behavioral Research*

Computer networks underpin virtually all aspects of biomedical research, from the capture, storage and analysis of genome sequences to the visualization of molecules, cells, and organs to the dynamic modeling of disease epidemics. Researchers increasingly turn to computing power at the teraflop scale and beyond, using petabyte resources, to conduct modeling and simulations of biological systems, creating exciting new scientific opportunities. But powerful computers alone are not enough to exploit those opportunities. A comprehensive supporting infrastructure (often termed cyberinfrastructure) must be in place, one that integrates data-gathering facilities, computing hardware, data analysis and informatics tools, interoperable software and middleware, and expertise needed to develop robust software applications and build, manage, and utilize networks. Network connectivity is increasingly important in view of ongoing fiscal constraints, especially for interdisciplinary team science, because it allows collaborative sharing of valuable data, expertise, and other research resources at optimal rates. Joint efforts to develop network infrastructure are therefore of great interest to federal basic science funding agencies and the communities they serve.

1.2 *Clinical and Translational Research*

The new model for clinical and translational research envisioned in NIH Roadmap for Medical Research (<http://nihroadmap.nih.gov/>) requires network connectivity that is fast, reliable and secure. Connectivity provides the means to efficiently manage large, multi-site clinical studies and to rapidly disseminate data to researchers for validation and further study. However, academic health centers in some locations, as well as many physicians' offices, rural hospitals, and clinics, have poor connectivity, limiting their ability to participate in research networks. Shortcomings extend beyond the physical network, including adoption of policies and procedures for seamless interoperability and data standards and security for all participating sites. Overcoming these barriers will greatly expand access to research tools and health information for physicians, patients, and researchers, both in academic health centers and wherever researchers conduct community-based research, including remote locations that rely on wireless technologies. Enhanced connectivity will also broaden access to education and training programs that further national efforts to strengthen the clinical research workforce.

1.3 *Health care quality, safety and effectiveness research*

The Agency for Healthcare Research and Quality (AHRQ) supports and conducts scientific studies to improve the access, effectiveness, and quality of primary and preventive health care services. One promising approach utilizes primary care practice-based research networks (PBRNs) comprising groups of ambulatory primary care

practices, often with affiliated academic or professional organizations, investigating questions relating to community-based practice and patient care. Connectivity extends the scope and reach of PBRNs, bringing evidence-based medical care to more communities and opening new avenues for collaborations with academic researchers to translate knowledge from pre-clinical and clinical studies into improved health outcomes. AHRQ also plays a critical role in the drive to improve health care delivery by advancing the use of health information technology (health IT) in primary care settings. As part of its initiative, AHRQ has funded grants and contracts in 41 states to support and stimulate investment in health IT, especially in rural and underserved areas. These projects constitute a real-world laboratory for examining health IT at work. AHRQ and its partners focus on identifying the challenges of health IT adoption and use, solutions and best practices for making health IT work, and tools that will help hospitals and clinicians successfully incorporate new technologies.

1.4 *Health Disparities in Underserved Populations*

NCRR supports programs to develop biomedical research capacity at minority-serving institutions and at academic institutions in states that historically have not participated fully in NIH-funded research. Owing to their locations and missions, these institutions afford unique opportunities to bolster inclusion of underserved populations in clinical and translational research, both as investigators and as research participants. Efforts to expand research activity at these institutions must address critical needs for better network connectivity. Enhanced connectivity will aid the development of an emerging translational research network focused on the causes and amelioration of health disparities in underserved populations. This network brings together clinician scientists supported by NCRR programs, other NIH-supported clinical research centers, and primary health care providers, including community health centers, to conduct multi-site clinical studies and community-based research designed to speed translation of knowledge into improved health outcomes. Consortium partners and participating sites require network connectivity for videoconferencing and access to computational tools, shared instrumentation, and a clinical data management system for collecting, storing and analyzing data from multiple sites. Enhanced connectivity will also boost access to research education and training programs at these institutions.

The Health Resources and Services Administration (HRSA) is the principal Federal Agency charged with increasing access to health care for those who are medically underserved. HRSA's portfolio includes a range of programs and initiatives designed to increase access to care, improve quality, and safeguard the health and well-being of the Nation's most vulnerable populations. Much of this work is accomplished through the funding of approximately 940 community health centers comprising nearly 3,600 health center sites that serve about 12.5 million patients. As part of its commitment to the national health information technology (health IT) goals, HRSA recently created an Office for Health Information Technology to provide strategic leadership and policy development around health IT as well as to explore opportunities to forge partnerships that result in better health care and health outcomes for the medically underserved.

Similarly, the Indian Health Service (IHS) provides a comprehensive health services delivery system for approximately 1.8 million of the nation's estimated 3.3 million American Indians and Alaska Natives. The Federal system consists of 33 hospitals, 59 health centers, and 50 health stations. In addition, 34 Urban Indian health projects provide a variety of health and referral services. IHS has long been a national leader in the development and use of electronic clinical information. For over 30 years, IHS and tribally operated health facilities have been using and improving their Resource and Patient Management System (RPMS), a comprehensive electronic healthcare information system composed of over 60 software applications that help streamline health care and evaluate clinical outcomes and processes. Modeled after the electronic medical record used across the Veterans Health Administration (VHA) hospital network, the RPMS electronic health record (EHR) supports a variety of clinical functional components. Advantages include a highly customizable user interface that can be modified to accommodate different information and workflow needs of various users, including biomedical and behavioral researchers.

1.5 Public health monitoring, biosurveillance, and situational awareness

The promise of epidemiologic networks to enhance national and global situational awareness is another primary driver for enhanced connectivity. Infectious diseases and their natural vectors defy containment within national borders or geographic regions. Timely collection and analysis of data and delivery of useful information is critical to develop effective predictive models to effectively address regional, national or global outbreaks. General recognition of network inadequacy and its impact on economic and health well-being provides an opportunity for federal agencies to address this situation proactively through industry and academic partnerships, focusing, for example, on biosensors networks and correlations between environmental exposures and health status, both in urban and in rural (including agricultural) settings.

1.6 Interdisciplinary research education and training

Enhanced connectivity at academic institutions strengthens interdisciplinary science education and training programs and furthers the nation's critical efforts to nurture a diverse biomedical research workforce. Toward that end, NCRR's Institutional Development Award (IDeA) Networks of Biomedical Research Excellence (INBRE) program supports on-line training and education opportunities for students in primarily undergraduate institutions in 22 IDeA-eligible states and Puerto Rico, including historically Black colleges and universities, Hispanic-serving institutions, tribal colleges and universities, and community colleges. For example, using enhanced connectivity, the Montana INBRE network, comprising two PhD-granting institutions, five baccalaureate colleges, six tribal colleges, and two research institutes, brings together researchers and undergraduate and graduate students in multi-campus, cross-state collaborative epidemiological studies of infectious diseases and environmental health risks.

Harnessing the full power of advanced computational facilities and computer networks

and their promise for research and education across all areas of science requires a workforce with the knowledge and skills needed to develop and exploit cyberinfrastructure. The new Cyberinfrastructure (CI)-TEAM program in the Office of Cyberinfrastructure at the National Science Foundation (NSF) signals a major federal commitment to join with the nation's science and engineering community in support of this goal. Recognizing the potential for cyberinfrastructure to expand access to state-of-the-art science and engineering research and education, the CI-TEAM program, like NCRR's programs, seeks to broaden participation of groups that are under-represented in science and engineering.

1.7 Health information dissemination to community providers & patients

Federal agencies support a wide range of outreach efforts to provide up-to-date health information to the general public and to health care providers and their patients. These include nationwide public campaigns designed to promote good health, requests for public input on sponsored programs, and special programs designed specifically to involve public representatives in the clinical research enterprise. In addition to promoting collaborations between primary care providers and researchers at academic health centers, enhanced connectivity to community health centers via research networks and to consumers via ubiquitous wireless technologies strengthens lines of communication for health messages and extends the scope and reach of these vital public education and outreach efforts.

The necessarily abbreviated set of research challenges and approaches listed above and in the following section illustrates the promise of network connectivity, enabling people, computation, shared instrumentation, and data to come together in space and time to address important and difficult problems and to achieve the missions of numerous federal R&D agencies. Solving all of these challenges is beyond the capacity of any one organization's resources. Working together, we can leverage existing cyberinfrastructure, produce metrics indicating best practices, and identify priorities for the biomedical research community to insure that agencies with mutual interests can make the most effective investments to maximize return on public investment.

2. KEY QUESTIONS AND CHALLENGES

2.1 Is existing network infrastructure adequate to support interdisciplinary research across the health science spectrum? Will refinement or expansion of current network models suffice to meet anticipated needs, or are new models needed?

Cyberinfrastructure is evolving rapidly, with investments from both the public and private sector. As they approach decision points toward future programs, government agencies must carefully weigh evolving network models. Regional optical networks (RONs) represent facility-based networking built with owned assets, in contrast to the Internet2 Abilene model of a research and education network (REN) with public shared assets. The workshop will address similarities and differences across regional strategies and ways that RON infrastructure relates to research support for government programs. A key consideration is the extent to which federal science agencies should invest further in national high-speed backbones. Ultimately these may become unnecessary for most purposes, but that is not the case today. Conversely, large national backbones, both NLR and Internet2, cannot meet current needs without RONs. So it is critical to define gaps and intersections between national backbones and emerging RONs.

“Condominium fiber networks” use customer-owned fiber links to commercial ISPs, often with unlimited bandwidth. This approach is increasingly popular among schools, universities, and businesses, but growing struggles over net neutrality, tiered pricing, and federal regulation suggest that current commercial high-speed internet market structures may impede future REN growth. Alternative models include transit exchanges (TXs) using municipal networks, which are relatively cheap compared to commercial ISPs. Like shopping malls, TXs need “anchor tenants,” e.g., universities, big healthcare systems, and public agencies. By building out “first-mile” links to increasingly ubiquitous fiber, universities and medical centers can bring their campuses to a RON via a TX. Key issues include incentives for ISPs to provide services at the TX and ways to integrate TXs into regional networks. Wireless mesh networks with built-in Peer2Peer protocols also merit consideration. Though P2P on a wireless mesh network is a breakthrough idea, enterprises must control information flow by building a Faraday shield around buildings and/or banning personal computing devices within the enterprise zone. This has significant implications for research and health care IT efforts.

Biomedical research requires dedicated infrastructure that offers high-performance network capacity and value-added services such as data security, privacy, database federations, and distributed computing. Network nodes include local, regional, national and international endpoints, including federal government research facilities, state public health laboratories, academic institutions, hospitals, community clinics and other healthcare centers. To serve this broad community, will new network structures be needed, beyond IP over commercial assets? If so, what should they encompass? Clearly they must be reliable, innovative and adaptive, fast, cheap, and simple to use. And do the needs of the health research community move beyond the objectives Internet2 is pursuing for the broader research and education space? Are there unique

aspects to health research needs? In order to create a sustainable business model, will next-generation networks need to provide value for the health care sector, where the big money is? One way to do this is to leverage the natural intersections between health research and health care and coordinate investments in IT infrastructure at those intersections. What kinds of data do we envision sharing over integrated health networks? Different kinds of data (e.g., text, still images, video streaming) require different network resources. Classification of biomedical data by required transmission rate could form the basis for assessment of existing network access, allowing cases to be made for upgrading bandwidth where necessary.

2.2 Is existing network infrastructure adequate to bridge academic health centers and community health care providers in order to foster and stimulate community-based clinical and translational research? If not, what are the gaps, what will it take to close them, and how should efforts to close them be funded and prioritized?

Researchers and health care providers share a vital stake in emerging health IT systems as emphasis shifts toward multi-site clinical studies and community-based translational research. The NIH Roadmap envisions a major role for health care providers in the research enterprise. Physicians and patients must work together with academic investigators to build versatile and secure networks to create opportunities for synergy and avoid needless duplication of efforts. For example, state-of-the-art optical networks, such as those being developed by the National Lambda Rail to provide interactively controlled imaging instruments with HDTV feedback for structural biology, also support new telemedicine applications, showing how advanced network architecture can serve multiple critical missions. However, health care providers, particularly those affiliated with relatively small practices, need real incentives to seek and utilize access to advanced networks, as well as training and resources for ongoing technical assistance. Building bridges must be guided by understanding value added for all stakeholders.

TATRC's HealthGrid concept offers one promising approach in which medical data can be stored, processed, and made easily available to researchers, physicians, healthcare organizations, the public health sector, health care administrators, and individual citizens. Paralleling the U.S. military's move towards "Net Centric Warfare", a "Net Centric Healthcare" environment can enable and enhance research, development, education and patient care within the Army and the Military Healthcare System (MHS) in general. With all necessary security guarantees, respect for ethics and observance of standard regulatory frameworks, such an infrastructure allows association of post-genomic information and medical data, opening up new ways to improve health care across a continuum of sectors. In the first decades of broadband technology and Grid computing, many of these potential benefits have not been realized. While challenges exist, they are not insurmountable; through concerted effort, a research roadmap and funding plan can be derived to address them in the next five years. A consensus that the use of Grid technologies for biomedicine is at a developmental "choke point" beyond

which a dramatic expansion of its utility and functionality can be realized makes it imperative to identify these challenges and craft a plan to surmount them in order to transform the practice of medicine and health care delivery as we know it.

2.3 What are the needs of minority-serving institutions and institutions in rural or remote areas, and how can these needs be addressed to enhance opportunities for broader inclusion in biomedical research?

Building on experiences from recent networking projects, successful approaches for identifying resources and optimal technologies can be realized. Lessons from the Lariat Project can guide next steps in extending advanced cyberinfrastructure to developing research, education, and healthcare institutions nationwide, including rural hospitals and clinics, minority-serving institutions, and tribal health organizations. This ambitious undertaking will require close collaboration among numerous federal science agencies, in partnership with academic and private sector organizations, to identify available resources and optimal technologies and approaches that recognize the varying needs of developing institutions and the diversity of driving research challenges at those institutions.

Potential partners include the National Center for Minority Health and Health Disparities at NIH and AHRQ and HRSA, which support research programs in community health centers. HRSA's Health Disparities Collaboratives (HDC) program supports research at some of the same community health centers involved in RCMI-supported Comprehensive Centers on Health Disparities. Lack of support for IT resources at many community centers is a major barrier to participation in research partnerships with academic health centers. HRSA HDCs have successfully implemented IT tools to improve learning and the spread of health care practice change. For example, their health disparities web portal gets 800,000 hits per month. A relationship between HRSA and NCRR programs could strengthen linkages between communities and relevant research, and bring cost savings due to adoption or adaptation of HRSA's IT tools by NCRR grantees to share information, encourage interaction, and disseminate research findings.

Similarly, TATRC's CERMUSA project in rural Pennsylvania addresses barriers to robust cyberinfrastructure for telemedicine applications and patient education. The use of expanded connectivity as a tool for education and information dissemination is critical. However, the education and training of individuals capable of maintaining and effectively using the enhanced cyberinfrastructure will be a substantial challenge, especially for underserved areas. Another major challenge is how institutions will pay for it, particularly smaller, rural institutions with limited existing infrastructure. Solutions will most likely involve ongoing costs. Equitable distribution of support is critical to avoid placing many smaller institutions in underserved areas at a major disadvantage. Negotiation of consortia arrangements with providers might be a useful route to explore in such areas.

Collaborations between federal R&D agencies, academic, and private sector organizations will be key to advancing a broad range of research activities and, given the diversity of challenges, must address an equally broad range of cyberinfrastructure needs. Whether for local area networks, campus backbones, or wide area networks linking investigators to colleagues around the globe, support for enhanced connectivity should be targeted to developing institutions in proportion to the scope of collaborative research and training activities, including collaborations with the broader science and education community.

2.4 Will the private marketplace and/or state and local governments be willing and able to shoulder the costs of developing and sustaining network infrastructure that meets anticipated research needs and ensures broad access to national and international research assets?

Partnerships with commercial organizations have been central to the development of cyberinfrastructure for biomedical research. For example, organizations such as Internet2 have found that corporate partners are critical for the development and ongoing operation of the Abilene Network, for moving forward advanced applications supporting research and education, and for ongoing technology transfer. Partners such as Qwest, Nortel, Cisco and Juniper Networks provided critical corporate contributions of service, product, and mindshare that helped to launch Internet2. Each commercial organization has a unique value proposition that motivates its involvement, yet all are focused on realizing the potential that advanced networking, middleware, and applications hold for research and education, and the opportunity to shape the future of the global Internet.

In addition to commercial networking technology providers, supporting cyberinfrastructure for biomedical research can serve the interests of content providers and organizations that serve technology consumers. Commercial organizations with an interest in the biomedical community and a connection to high-performance networks can benefit by being plugged into a unique worldwide technology testbed where they can work together, develop prototypes, and move the resulting technologies into production and regular use. For example, Internet2's corporate members are incorporating advanced technologies into product prototypes, using new interactive collaboration applications to connect scientists at globally distributed laboratories, and developing new forms of advanced media. This type of relationship benefits both early-stage and established companies from diverse sectors.

Although the private marketplace clearly has an interest in research networks, can the marketplace be relied upon to develop those networks and sustain them over the long term, or is continued federal support essential? Should the federal government facilitate provision of local and regional network services, e.g., subsidize RON build-outs, to insure that national research and health care IT assets are readily accessible?

In particular, how will academic researchers provision the network infrastructure needed

to support community-based clinical, translational, and health services research in partnership with health care providers, especially in underserved regions? If the government is to continue play a key role in sustaining computer networks for such purposes, should federal agencies provide direct grant support for connectivity infrastructure, akin to other resources like shared instrumentation, or should support for connectivity continue to come primarily from indirect cost recovery, like basic utilities such as water and electricity?

2.5 If further development and expansion of research networks requires federal support, how can funding agencies balance the needs of their own missions against opportunities for collaboration where mutual interests exist? If collaborative approaches are warranted, how will agencies ensure adequate planning, coordination, and evaluation of inter-agency programs?

A key step toward future collaborations will be to get a better handle on the inventory of publicly and privately supported cyberinfrastructure programs, including regional and national networking activities, that impact health research and health care. Key questions include: Who is doing what where? How do existing and planned future network infrastructures support the desired research, education, public health, and clinical activities? Do we have a good enough vision of what that infrastructure environment looks like so we can focus on the resources necessary to improve and sustain it? Key stakeholders could address these questions through a national coordinating body comprising academic, industry, community, and government (federal, state, local, and tribal) partners, perhaps along the lines of the American Health Information Community but with a research purview.

Whatever shape the evolving network infrastructure takes, specific criteria will need to be established for evaluating outcomes measures, process measures, fiscal measures, security, interoperability, and quality of service. Programmatic evaluation should include measures of stable bandwidth available on demand; traffic volume before and after connectivity upgrades; the number and productivity of networked research projects (e.g., patient recruitment, publications); productive virtual meetings (e.g., via Access Grid); remote access to and utilization of advanced instrumentation and other distributed resources; and implementation and utilization of online education and training programs.

3. EMERGING NETWORKS AND TEST-BED PROJECTS

3.1 *Regional Research and Education Networks and Public-Private Partnerships*

Our nation's research and education communities have come to recognize and embrace the power of high-speed networks for meeting their objectives. For example, the Lonestar Education And Research Network (LEARN) is a cooperative effort of 33 institutions of higher education in Texas to provide high-speed connectivity between their institutions and to research networks across the country in support of their research, teaching, health care, and public service missions. The LEARN network is intended to enhance the state's research and economic competitiveness and provide state-of-the-art, cost-effective data communications that enable effective education of students around the state. Similar efforts in other regions include exemplary public-private partnerships. For instance, the Southeastern Universities Research Association (SURA) and AT&T entered into an agreement in 2003 providing SURA with no-cost access to 6,000 pair miles of dark fiber on AT&T's network and an additional 2,000 pair miles for network research. In part, SURA's goals are to increase collaboration of regional bioinformatics resources with a view toward establishing a regional BioGrid.

3.2 *IDeA Networks of Biomedical Research Excellence (INBRE)* <http://www.ncrr.nih.gov/resinfra/inbre.asp>

NCRR's INBRE initiative supports statewide networks for biomedical research, education, and training in 22 states and Puerto Rico. Much like SURA's aim to build regional bioinformatics resources, each INBRE network supports a bioinformatics core facility to provide critical access to distributed databases, informatics tools, and training for undergraduate and graduate students engaged in research in a wide variety of urban, rural, and minority-serving institutions. INBRE-affiliated medical schools are well positioned to address national needs in developing a diverse, inclusive research workforce that is well versed in the use of biomedical informatics, both for health research and for health care.

3.3 *Lariat Project* <http://lariat-west.org/>

NCRR's Lariat Project is a collaborative regional networking effort bringing high-speed connectivity to biomedical researchers in a consortium of academic institutions in Montana, Idaho, Nevada, Wyoming, Alaska, and Hawaii. The project has installed dedicated research network links from each site to the Abilene backbone and the National Lambda Rail via regional points-of-presence in Seattle, Denver, and Sunnyvale, and to major bioinformatics resources at the University of Washington. Lariat cyberinfrastructure eliminates crippling choke points, ensures scalable growth, and enables provision of dedicated bandwidth for specific research applications and science education. Enhanced connectivity allows local scientists and educators to take

advantage of the wealth of remote research resources and expertise available across the U.S. and around the world.

3.4 *Biomedical Informatics Research Network (BIRN)*

<http://www.nbirn.net/>

NCRR's BIRN project has been established to utilize emerging advanced cyberinfrastructure to enhance collaborative efforts, integrating data, expertise, and unique technologies from multiple research centers to spur important scientific advances that would be difficult or impossible in the context of individual laboratories. Launched in 2001 with a coordinating center and two test beds and a third test bed added in 2002, the BIRN now involves a growing consortium of more than 20 universities and 30 research groups across the country, with additional connections being made with the international community of neuroinformatics researchers. BIRN test beds emphasize data sharing, integration, processing, and analysis. Although they focus on neuroimaging of human neuropsychiatric disease and associated animal models, the underlying infrastructure for collaboration will be of great value in all areas of biomedical and clinical research. Because very large imaging data sets, in terms of file size and number of files, are being collected at many sites and stored in a distributed fashion, the BIRN stresses the high-speed network to which all sites are connected. It provides fertile ground for testing how to balance moving cycles to the data versus moving data to the cycles, and how to aggregate the results of large automated workflows into meaningful but compact human-readable forms. The BIRN is also addressing some very large computational problems that require grid computing approaches.

3.5 *Models of Infectious Disease Agent Study (MIDAS)*

<https://www.epimodels.org/midas/about.do>

MIDAS is a collaboration between research and informatics groups to develop computational models of interactions between infectious agents and their hosts, disease spread, prediction systems, and response strategies. The models will be useful to policymakers, public health workers, and other researchers who want to better understand and respond to emerging infectious diseases. If a disease outbreak occurs, the MIDAS network may be called upon to quickly develop specific models to aid public officials in their real-time decision-making processes.

3.6 *National Centers for Biomedical Computing (NCBC)*

<http://www.bisti.nih.gov/ncbc/index.cfm?>

Progress in biomedical computing requires cross-disciplinary expertise. Supported by NIH, the NCBCs and the teams they bring together produce investigators with broad knowledge that can be applied to biomedical issues, knowledge that incorporates the strengths of biology, computer science, and mathematics. In the short term, biomedicine will benefit from the team approach. In the long term, the NCBCs will build a cadre of researchers who can apply much of the expertise necessary to deploy and support

biomedical computing and advance the emerging discipline of systems biology. The trans-NIH Biomedical Information Science and Technology Initiative (BISTI), and its NCBC program, is a bootstrapping approach to that next level of interdisciplinary biomedical science.

3.7 *Cancer Bioinformatics Grid (caBIG)*

<https://cabig.nci.nih.gov/>

The cancer Biomedical Informatics Grid (caBIG™) is a voluntary network or grid connecting individuals and institutions to enable sharing of data and tools, creating a World Wide Web of cancer research. The goal is to speed the delivery of innovative approaches for the prevention and treatment of cancer. The infrastructure and tools created by caBIG also have broad utility outside the cancer community. Over 800 people from more than 80 organizations are working collaboratively on over 70 projects in a three-year pilot project. caBIG is already delivering tools and applications, all freely available to the community and other interested stakeholders. Program milestones, an inventory of tools developed or being developed, guidelines, and papers produced by the caBIG community are available on a public Web site.

3.8 *National Ecological Observatory Network (NEON)*

<http://www.neoninc.org/>

Supported by NSF, the NEON is the first national ecological measurement and observation system designed both to tackle regional- to continental-scale scientific questions with the interdisciplinary participation needed to achieve credible ecological forecasting and prediction. The NEON is envisioned as a continental-scale research instrument consisting of geographically distributed infrastructure comprising cutting-edge lab and field instrumentation, site-based experimental infrastructure, natural history archive facilities and/or computational, analytical and modeling capabilities, all networked via state-of-the-art communications. Scientists and engineers will use NEON to conduct real-time ecological studies spanning all levels of biological organization and temporal and geographical scales. Data will be made publicly available on the Web.

3.9 *AHRQ National Resource Center for Health Information Technology*

<http://healthit.ahrq.gov/portal/server.pt?>

The National Center for Health IT is a Web-based learning resource center for health care providers seeking help in adopting health IT, including a library with links to more than 5,000 resources identified by AHRQ experts and partner contributors, such as professional societies and nonprofit organizations. Health care providers can receive an IT evaluation toolkit, a summary of key topics such as clinical decision support and health information exchanges, and other resources including current health IT activities and funding opportunities. The center aims to help health care providers at the ground level learn from each other's real-world experience and have easy access to the best information available, bringing lessons of experience together in one place so that providers can avoid problems and achieve greater benefits when they adopt health IT.

3.10 *Electronic Primary Care Research Network (ePCRN)*

<http://www.epcrn.org/index.php>

Funded by the NIH Roadmap Initiative and administered by the Federation of Practice Based Research Networks, the ePCRN allows primary care practices to link with researchers conducting clinical research anywhere in the United States. Its principal aim is to enable the development of an electronic infrastructure that facilitates recruitment of subjects and performance of randomized controlled trials in primary care practices throughout the U.S. This infrastructure, which includes distributed database technology interfaced with a web portal solution and Internet2 components for enhanced functionality and communication, is designed to promote rapid integration of new research findings into primary care practice.

3.11 *Center of Excellence for Remote and Medically Under-Served Areas (CERMUSA)*

<http://www.cermusa.org/>

Principally funded by TATRC, CERMUSA demonstrates and assesses best practices in providing healthcare services and education utilizing appropriate, available technology to serve the needs of remote and medically under-served areas. CERMUSA's Telehealth prototypes use computer and communications technology to provide medical services via teleconferencing, including clinical specialty consultations and assistance in surgical procedures. Telehealth resources also enable general practitioners and other health care providers to receive education and training on various subjects from specialists anywhere in the world. Partnerships with rural healthcare organizations are developed to explore the feasibility, reliability, and impact of advanced telecommunications, wireless technologies, and medical information systems and then to compare, contrast, and analyze the types of medical information technologies that will meet the needs of the community and its hospital in the delivery of health care services. CERMUSA also has an education mission, helping students learn about the potential value of Internet2 for providing enriching educational content. CERMUSA workshops in rural school districts feature demonstrations of various tools to make effective use of the huge data handling capability of Internet2.

Appendix 1.

EXECUTIVE SESSION PARTICIPANTS (n=82)

Biomedical researchers (~40%)

- basic science
- clinical & translational research
- primary care physician research networks

Non-federal computer scientists and networking experts (academic and corporate; ~35%)

Federal agency staff (~25%)

- NCRR, NLM, NIGMS, NCMHD
 - DoD/TATRC
 - NSF Office of Cyberinfrastructure
 - VHA Health IT Sharing
 - HRSA Office of Health IT
-

Appendix 2.

DETAILED PARTICIPANT LIST

Appendix 3.

WORKSHOP PRESENTATIONS

- **Lariat Project**
Gwen Jacobs, Ph.D., Montana State University
 - **Biomedical Informatics Research Network (BIRN)**
Mark Ellisman, Ph.D., Univ. of California, San Diego
 - **RCMI Translational Research Network**
Keith Norris, M.D., Charles R. Drew University of medicine and Science
 - **Biomedical Computing Collaboration Challenges**
Chris Johnson, Ph.D., University of Utah
 - **Center of Excellence for Remote & Medically Underserved Areas**
Mike Shanafelt and Rob Dillon, St. Francis University/CERMUSA
-

Appendix 4.

About NCRR

http://www.ncrr.nih.gov/about_ncrr/mission.asp

The National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), provides laboratory scientists and clinical researchers with the environments and tools they need to understand, detect, treat, and prevent a wide range of diseases. This support enables discoveries that begin at a molecular and cellular level, move to animal-based studies, and then are translated to patient-oriented clinical research, resulting in cures and treatments for both common and rare diseases. NCRR connects researchers with one another, as well as with patients and communities across the Nation, to harness the power of shared resources and research.

About TATRC

<http://www.tatrc.org/>

The Telemedicine and Advanced Technology Research Center (TATRC), a subordinate element of the United States Army Research and Materiel Command (USAMRMC), is charged with managing core Research Development Test and Evaluation (RDT&E) and congressionally mandated projects in telemedicine and advanced medical technologies. To support its research and development efforts, TATRC maintains a productive mix of partnerships with federal, academic, and commercial organizations. TATRC also provides short duration, technical support (as directed) to federal and defense agencies; develops, evaluates, and demonstrates new technologies and concepts; and conducts market surveillance with a focus on leveraging emerging technologies in healthcare and healthcare support. Ultimately, TATRC's activities strive to make medical care and services more accessible to soldiers, sailors, marines, and airmen; reduce costs, and enhance the overall quality of military healthcare.

About Internet2

<http://www.internet2.edu/about/>

Internet2 is a consortium being led by 207 universities working in partnership with industry and government to develop and deploy advanced network applications and technologies, accelerating the creation of tomorrow's Internet. Internet2 is recreating the partnership among academia, industry and government that fostered today's Internet in its infancy. The primary goals of Internet2 are to create a leading edge network capability for the national research community, enable revolutionary Internet applications, and ensure the rapid transfer of new network services and applications to the broader Internet community.
